



World Alliance of
Pituitary Organizations

Activity Report 2024

INTRODUCTION

In October 2014, it was already **10** years since patient organizations decided to start a new and independent patient organization, which would embrace most pituitary and adrenal insufficiency disorders.

Since then, numerous projects and global summits have been organized and participated in by WAPO. Currently WAPO represents 51 patient organizations in **36** countries!

In 2024, we have extended our collaboration with El Cuore for the designs and creative support they provide. After receiving support in 2023, we invited Caretently Health Communications' assistance with the 2024 Blogs & Vlogs series incl. social media blasts and awareness campaigns.

WAPO wishes to express our special gratitude to pharmaceutical companies. With their support, in-kind and financially, it has been feasible to execute the WAPO activities and ideas for the year 2024. Although WAPO is an official charity, we do not receive government funding.

We eagerly anticipate the continuation of our collaboration with all WAPO Member organizations and all stakeholders in 2025.

The WAPO Board of Directors,
Sandra, Clive, Robert & Muriël

December 2024

WAPO Board of Directors

The Board consists of the following members, who were (re-)elected for a period of 3 years, in 2022:

Mrs. Muriël Marks	Board member
Mrs. Sandra Mesri	Board member
Dr. Clive Deverson	Board member
Mr. Robert Brady	Board member

WAPO Board activities

Due to different locations of Board members, we held 16 online board meetings in 2024. Pre- and after the WAPO 2024 Global Summit, the board held meetings in person, to discuss a broader spectrum of topics.

WAPO committee structure

Since 2021 WAPO works within the following committee streams:

- 1. Operations** – incl. Daily business, Finances, Strategy, IT, Summit & AGM, and Memberships.
- 2. Awareness & PR** – incl. Awareness campaigns, Data collecting and Member Support.
- 3. Communications** – incl. 'Blogs & Vlogs'.

WAPO Member Organizations

WAPO has officially welcomed 3 new member organizations in 2024:

- **Acromegaly India Community**, India (April, 2024)
- **Danish Acromegaly Association**, Denmark (June 2024)
- **Swedish Addison Group**, Sweden (October 2024)

Per December 31, 2024, WAPO is representing 51 patient organizations, in 36 countries, who are focusing on various disorders, e.g. pituitary, adrenal and related rare diseases.

WAPO reached out to patient organizations who haven't been active for the past 2-3 years whether they will extend their member/partnership in 2025. We aim to have an active community.

WAPO Medical Advisory Board

Per January 2024, the Medical Advisory Board is represented by the following healthcare professionals:

Christine Yedinak	Associate Professor and nurse practitioner at OHSU, USA
Diego Ferone	Professor of Endocrinology at University of Genova, Italy
Federico Gatto	Assistant Professor in Endocrinology at University of Genova, Italy
Garni Barkhoudarian	Neurosurgeon at Pacific Neuroscience Institute, USA
Debóra Katz	Director Neuroendocrinology at FLENI Hospital Buenos Aires, Argentina
Elena Valassi	Associate Professor Endocrinology, International University Catalonia, Spain

The WAPO Board of Directors is very thankful to all medical advisors for their support in 2024!

OPERATIONS

Finances

In 2024, the WAPO bookkeeping was executed internally and supported by an external company, with which WAPO collaborates since 2020.

The Annual membership fee will be invoiced through PayPal.

Annual General Meeting

During the online Annual General Meeting of June 19, 2024 the WAPO Board of Directors were granted **'APPROVAL'** for 'All WAPO 2023 Activities as well as 2023 Finances' through a voting survey. We received 27 votes, where we needed quorum of 25+1 votes.

We also inserted the question whether patient organizations do reshare WAPO products, like vlogs & blogs or survey, etc. and all voting member organizations were positive, with 2 remarks: 1. If in Spanish and 2. If disorder specific content.

The WAPO Board feels very supported with these outcomes!

During the 2024 AGM (program for patient advocates present at the Summit) on October 6th, we discussed 1 'Affiliate Membership' for other medical stakeholders, e.g. physicians, nurses, GP's, and 2. raise of membership fee.

IT

Since 2019, WAPO has collaborated with the Dutch IT services company 'Kwaaijongens', specialized in 'WordPress' websites and M365 support.

Creative Designs

Since 2018 WAPO has collaborated with the company El Cuore in Argentina.

In 2024, El Cuore has supported WAPO with the following activities:

- Survey logo 'AVP-D | CDI' survey;
 - WAPO Global Summit 2024 – 2 banners, logo's and event app images;
 - WAPO flyer 2024
 - Awareness campaigns: Pituitary Month disease posters (see example) and Acromegaly Day video.
- Example: Arginine Vasopressin Deficiency poster

WALK WITH WAPO THIS OCTOBER FOR PITUITARY AWARENESS MONTH AND LEARN ABOUT ARGININE VASOPRESSIN DEFICIENCY/CENTRAL DIABETES INSIPIDUS

Arginine Vasopressin (AVP) Deficiency (AVP-D), formerly known as central diabetes insipidus, is a rare pituitary disorder characterized by a decreased production or release of arginine vasopressin, a hormone which signals to the kidneys to retain water.

01 SYMPTOMS INCLUDE

- Extreme thirst, iced water craving
- Frequent urination
- Dry mouth, lips and skin
- Weakness
- Fatigue
- Loss of appetite
- Confusion
- Headache
- Waking up at night to drink and pass urine

"My first symptoms were very frequent and large, nearly colorless urinations and an unquenchable thirst. I urinated over 7 liters of urine in 24 hours!"

02 DIAGNOSIS IS BASED ON

- Presence of symptoms
- Blood sodium level and urine tests
- MRI imaging
- Water deprivation test
- New Copeptin-based stimulation tests

"When my daughter was diagnosed with AVP deficiency it had a major impact on the whole family."

03 MANAGEMENT AND TREATMENT

- Desmopressin (synthetic AVP)
- Symptoms such as changes in urinary frequency/volume and strong thirst must be monitored due to a risk of hyponatremia (low blood sodium)

"I quickly found out that managing it was much more complex and required monitoring on a daily basis."

04 LONG-TERM CHALLENGES

- This condition comes with invisible disabilities that need to be considered.
- Currently the only way to measure blood sodium levels is at a lab. A home blood sodium meter would make managing AVP-D easier and safer.
- Educating patients and healthcare teams about the risk of hyponatremia when taking desmopressin is still urgently needed.

"It's almost impossible to explain to someone who doesn't have my condition, which often leads to misunderstanding."

WAPO
World Alliance of Pituitary Organizations

LEARN MORE AT WWW.WAPO.ORG

WAPO ACTIVITIES IN 2024

WAPO Global Summit 2024

In 2024 the WAPO Global Summit was held in Leixlip, Ireland on October 4-5-6, 2024.

The Springfield Hotel in Leixlip was a good venue for the Summit.

All sessions were hosted by Clive Deverson (WAPO Board) and most topics were followed with Q&A or discussion. In total 26 patient advocates were present from across the globe, e.g. Australia, India, China and Europe.

All sessions were available to follow in English and Spanish, with 2 interpreters on location, and were recorded in both languages for sharing on the WAPO website, see: <https://www.wapo.org/library/>

The 2024 Summit was made possible with support of the following companies:

Gold Level: Recordati Rare Diseases; **Silver level:** IPSEN, ESTEVE | HRA Pharma Rare Diseases, Novo Nordisk, Crinetics, Camurus and at **Bronze level** (as a first time sponsor): H. Lundbeck A/S

We would like to thank all pharmaceutical companies for their great support and input during the meeting with the WAPO Board, and presence during the program of the WAPO Global Summit in 2024!

We thank all speakers for their interesting presentation on the below topics and presence during the program. You will find the recorded presentations on the WAPO website Library/Summit:

Please find the topics presented during the Global Summit program below:

- * *Travelling with a Hidden Disability*
- * *How to improve the diagnosis journey*
- * *Genetics,*
- * *Harmony & Wellness support for pituitary & adrenal patients*
- * *Process of a survey study*
- * *Arginine VasoPressin Deficiency | Central Diabetes Insipidus study and outcomes*
- * *Comorbidities in Endocrine Disorders*
- * *Availability of psychological therapies for patients affected by pituitary pathology*
- * *Acromegaly study in the USA*
- * *New formulations in treatment of Acromegaly patients and the patient compliance*
- * *A session where active music could support well-being*
- * *Adrenal Insufficiency and glucocorticoid withdrawal syndrome: 'Are they the same? How should we manage them?'*
- * *Power of Collaboration*
- * *Start up patient organization experiences*
- * *Engagement and Fundraising approaches*
- * *Round table discussions on various topics*

Responses participants:

Industry representative: *I just wanted to thank you and your team for a wonderful few days. The agenda was full and interesting, and I came away feeling very inspired by the work that is being done. Thank you for making me feel so welcome.*

Delegate:

It's my first time here, and I didn't know what to expect. It was a really fantastic experience to discuss my disease and journey with colleagues who have experienced the same. Thank you for this.

Delegate: *It was the first time I met people with the same disease!*

Delegate: *Thanks for a most inspiring and invigorating weekend! Hope to see you all back next year.*

Industry representative: *Thank you so much for the great meeting of last week and for having us to listen and to participate to the event.*



Patient Advocates of Pituitary & Adrenal Patient Organizations, Guest Speakers and Industry Representatives

WAPO 2024 Blogs & Vlogs Series

After 2 years of Webinar Series, WAPO considered a new method to assist and inform patient organizations, patient advocates, patients, caregivers, health care professionals, nurses and other stakeholders. This became the '2024 Blogs & Vlogs Series' with 5 Blogs and 5 Vlogs. We again collaborated with Caretently Health Communications and for technical support with the Production Man (England). And, like in previous years, we invited Patricia Vega to interpret and translate all information into Spanish.

In the end we could conclude we made 6 Blogs and 4 Vlogs, and a video, due to the unavailability of speakers.

We would like to thank Shari Dawson (patient advocate, Australian Pituitary Foundation) for her support with creating the blogs in Mailchimp.

WAPO especially wishes to thank the pharmaceutical companies who supported us and made the '2024 Blogs & Vlogs Series' possible: IPSEN, Recordati Rare Diseases and ESTEVE | HRA Rare Diseases.

Check out: <https://www.wapo.org/blogs/> or https://www.wapo.org/library/?_library_category=vlogs

Released WAPO Blogs and Vlogs 2024 topics:

Blog 1: Navigating Nutrition and Pituitary Disorders

Publication date: January 25, 2024

<https://www.wapo.org/navigating-nutrition-and-pituitary-disorders/>

Vlog 1: What makes a successful patient-healthcare professional relationship? With Els Rutten

Publication Date: February 29th, 2024

<https://youtu.be/xR4FsfKpLtU?si=VSv6RVwtvav6bs6l>

Blog 2: Collaborations between Patient Advocacy Groups and Pharmaceutical Companies – Clive Deverson

Publication date: March 21st, 2024

<https://www.wapo.org/collaborations-between-patient-advocacy-groups-and-pharmaceutical-companies/>

Vlog 2: Shining Light on Arginine Vasopressin Deficiency (AVP-D) / Central Diabetes Insipidus; with Pat Gildroy

Publication date: April 25th, 2024

https://youtu.be/wD-9jppHs58?si=_BdqTzrhCG3PzGkT

Blog 3: Top Tips for Travelling with a Pituitary Disorder

Publication date: May 23rd, 2024

<https://www.wapo.org/top-tips-for-travelling-with-a-pituitary-disorder/>

Blog 4: 2024 WAPO Blogs and Vlogs: Mid-Year Recap and What's Coming Next

Publication date: June 27th, 2024

<https://www.wapo.org/2024-wapo-blogs-and-vlogs-mid-year-recap-and-whats-coming-next/>

Vlog 3: Cushing Syndrome Comorbidities: Priorities for Patients vs Healthcare Professionals

Speakers: Dr. Noa Tal and Haleh Sharafi

Publication date: August 29th, 2024 (delayed due to speaker availability)

<https://youtu.be/kvT94sQIVT0?si=M3JDXHbHNR97peds>

Blog 5: Why raising awareness for pituitary disorders is so important

Publication date: October 24th, 2024

<https://www.wapo.org/2024-wapo-blogs-and-vlogs-why-raising-awareness-for-pituitary-disorders-is-so-important/>

Vlog 4: Pregnancy and Motherhood with a Pituitary Disorder

Speakers: Claire Barlow and Jennifer Kenworthy

Publication date: September 26th, 2024

<https://youtu.be/nCf9TzqyFbw?si=rwNgITPvhnjUtrQe>

Blog 6: **Hidden aspects of pituitary disorders central to Walk with WAPO campaigns**

(substitute for Vlog 5 as no speakers available)

Publication date: December 5th, 2024

<https://www.wapo.org/2024-blogs-and-vlogs-hidden-aspects-of-pituitary-disorders-central-to-walk-with-wapo-campaigns/>



WAPO Awareness Activities

Creating awareness for pituitary and adrenal disorders is always important. The WAPO Board decided to reuse the 2023 campaign for Cushing's and Adrenal Day. For Pituitary Month (October) and Acromegaly Day (November 1st) the Board decided to renew the campaigns. We invited Natasha Barr (Caretently) to think with us. The following campaigns were defined:

1. **Pituitary Month October**: 4 infographic posters on 'Acromegaly, Cushing's, adrenal insufficiency and AVP-D' were created, focusing on disease symptoms, treatment information. We invited patient advocates and people living with the above diseases, to share their experiences, and select 3-4 questions of a list of 25 questions. These answers were shared in the posters as well.

Medical information was checked by WAPO Medical Advisors, as well as Dr Atila Cihan (Switzerland) and Dr Noa Tal (USA) for which we like to thank them.

Please check out the posters: <https://www.wapo.org/awareness-for-pituitary-diseases-in-october/>

2. **Acromegaly Video** for November 1st: We created an overview of questions, with Dr Noa Tal, and asked people living with Acromegaly, to pick 3-4 questions, and answer these via voice-recording or video. Natasha Barr (Caretently) supported us with the process of the video.

We invited patient advocates and patients living with Acromegaly to share their experiences during diagnosis, treatment and after treatment, which recordings were used in the video.

Please watch the video: <https://www.wapo.org/walk-with-wapo-through-the-experiences-of-people-living-with-acromegaly/>

Both projects will be shared on the WAPO website or via World Alliance of Pituitary Organizations-YouTube.

Rare Disease Day – February 28 2023

Also in 2023, WAPO participated in the Rare Disease Day campaigns, while promoting and resharing campaigns and informing the patient organizations of the campaign kits (e.g. banners, posters, etc.) which were provided.

European Hormone Day – April 24 2024

WAPO participated and reshared the ESE toolkit for ‘European Hormone Day’ with member organizations. On April 24th, we promoted the EU Hormone Day.

In a feedback survey, we have called for an annual ‘International Hormone Day’.

Cushing’s Day

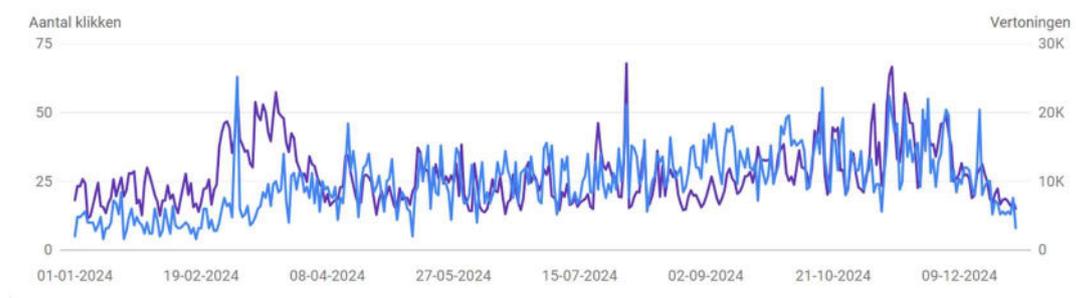
Due to limited time, we reshared earlier campaigns and supported other campaigns with resharing.

Addison’s Day | Adrenal Insufficiency – May 29 2023

WAPO reshared several campaigns.

WAPO Social Media Statistics

In 2024, WAPO was present on various social media platforms. Below image does show an overview of the website views and clicks during 2024.



WAPO.org:	9,1k Clicks and 3,97mln views (Source: Google Analytics)
Facebook General page:	925 followers
LinkedIn:	833 followers
X:	456 followers
Instagram:	301 followers

WAPO Code of Ethics

WAPO’s Code of Conduct for member organizations has been reviewed and renamed in 2024. During the WAPO Global Summit the new name was introduced and accepted: WAPO Code of Ethics. All member organizations received an email with the new version and an invite to under scribe the content.

EXTERNAL PROJECTS

In 2024, WAPO participated in several external projects, organized by various stakeholders. Most agreements limit the sharing of details on the projects. Therefore WAPO will share general project information below:

- **Identify a patient** with Acromegaly, to share information and experiences for Hidden Disabilities Sunflower website. See: <https://hdsunflower.com/uk/insights/post/acromegaly>
- **Identify a patient advocate** to share information and experiences with Cushing's for Hidden Disabilities Sunflower website. See: <https://hdsunflower.com/us/insights/post/cushings-syndrome>
- **Several interviews** supporting projects of stakeholders
- **Identify patients and patient advocates** for several interviews and projects.
- **Project participation:** Design and support a Cushing's survey with Red Thred Solutions (France) and H Lundbeck A/S.
- **Project participation:** Arginine VasoPressin Deficiency Survey (Adult patients)
Collaboration with Pat Gildroy, of 'Got AVP-D | Got DI?' facebook group and Histiocytosis association, supported by Dr Cihan Atila (Research Group|Clinical Neuroendocrinology of the University Hospital Basel, Switzerland).
The survey included questions on the diagnosis, treatment, and change of name from Central Diabetes Insipidus into AVP-d.
WAPO contributed in person and in funding the SurveyLab platform.
The project timeline started with a first call in September 2023 and presentation of the first results at the WAPO Global Summit 2024. In total, **891** completed surveys were received.
Recently, we have started discussions for a survey for health care professionals and Nurses, in collaboration with Chris Yedinak (FINE, OHSU USA) and Pat Gildroy, of 'Got AVP-d?'.
- **Support in resharing the 'Dreams Survey – Evaluation of Sleep Quality in Patients with Pituitary Disorders'** by the Research Group|Clinical Neuroendocrinology of the University Hospital Basel, Switzerland.

DATA & MAPPING

The WAPO Mapping Project III is still planned and has been postponed till 2025.

WAPO PARTNERS AND MEMBERSHIPS

WAPO is always looking for valuable partnerships with which all parties we can support patient organizations and their members.

In 2024 WAPO is collaborating or connected with the following organizations and companies:

- * AdrenalNET – www.adrenals.eu
- * European Society of Endocrinology (ESE) / European Congress of Endocrinology (ECE)
- * EURORDIS
- * FindMeCure
- * Federation of International Nurses in Endocrinology (F.I.N.E)
- * GAFPA (Global access for Patient Advocacy)
- * Hidden Disabilities Sunflower
- * International Alliance of Patient Organizations (IAPO)
- * International Society of Endocrinology (ISE)
- * Latin Patient Academy (LAPA)
- * Patient Focused Medicines Development – PFMD and the Synergist, PEOF
- * Pituitary World News

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